

Measuring Community Living Outcomes, Participation, and Quality of Life



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Quality of Life

- Broad multidimensional concept :
positive & negative aspects
- Measurement is challenging, complex
- Multiple domains
 - Health
 - Employment
 - Education
 - Housing
 - Environment (neighborhood)
 - Services/supports
 - Culture, values, spirituality

Health Related Quality of Life

- Aspects of overall quality of life affecting physical or mental health

Individual Level

Physical & mental
health perceptions
Health risk & conditions
Functional status
Social support
Socioeconomic status

Community Level

Resources
Conditions
Policies
Practices

Health Related Quality of Life

- Important component of health surveillance
- Valid indicators of service needs and intervention outcomes
- Self-assessed health status – powerful predictor of mortality and morbidity
- Impact of health on quality of life
- Self reported chronic diseases and risk factors

Health Related Quality of Life

- Burden of preventable diseases, injuries, disabilities
- Monitor progress – Healthy People
- Identification of subgroups in need of attention
- Help guide quality improvement interventions
- Health policies, legislation, resource allocation
- Older adults – life expectancy, disability

HRQOL Program

**CDC NATIONAL CENTER
FOR CHRONIC DISEASE
PREVENTION AND
HEALTH PROMOTION,
DIVISION OF ADULT AND
COMMUNITY HEALTH**

Diabetes in Spinal Cord Injury/Disorder

- 20% higher in veterans with SCI/D
- 3 times more than in general population
- More comorbidities, slow-healing foot scores, poorer quality of life
- Prevention/early intervention critical

BRFSS 2003
18,372

La Vela et al, 2006

Health, Secondary Conditions, Employment Outcomes & Disability

- 3, 076 adults with disabilities from BRFSS
- Exercise increased by 8.4% the probability of employment
- Health promotion is very important

Ipsen CJ, 2006

- Measuring health-related quality of life in persons with disabilities can be problematic due to differences among people and/or changes within people regarding internal standards, values on conceptualization of health-related quality of life.

Schwartz et al, 2007

Disability Data Infrastructure

- Federal costs with programs - \$226 billion/year
- Data inconsistent, program specific, no accurate analysis
 - Who and how many are benefiting?
 - To what extent people draw on multiple programs?
 - What specific services are provided and to whom?
 - How effective are they? What are the outcomes?
 - Are there state variations over time?
 - How are services integrated?




National
HCBS
Quality
Enterprise



CMS/AHRQ



Housing
Data



Mathematica
Policy
Research &
HHS ASPE

Affordable Care Act – Key Provisions for Public Health and Data Collection

Section 4302 concerned with data collection, analysis and quality related to understanding of health disparities.

Provisions affect data collection, analysis and reporting in HHS and also specifically the Current Population Survey (Bureau of Labor Statistics in Dept. Labor) and the American Community Survey (Bureau of Census in Dept. of Commerce).

Applies to “any federally conducted or supported health care or public health program, activity or survey.”

Conclusions

- Many changes in and new disability data collection standards are expected.
- Futures is bright for health services researchers.
- Quality indicators/measures that go beyond disease focus should be developed.
- Quality improvement interventions will help us reduce or eliminate disparities.

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THANK YOU!

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